

PADRECC POST

Spring 2011

THE PHILADELPHIA VA PARKINSON'S DISEASE RESEARCH, EDUCATION AND CLINICAL CENTER

Parkinson's Disease is Added to List of Presumptive Illnesses for Vietnam Veterans Exposed to Agent Orange VA Publishes Final Regulation on August 31, 2010

News Release from Department of Veterans Affairs, Office of Public Affairs, August 30, 2010:



In practical terms, Veterans who served in Vietnam during the war and who have a "presumed" illness don't have to prove an association between their medical problems and their military service. By helping Veterans overcome evidentiary requirements that might otherwise present significant challenges, this "presumption" simplifies and speeds up the application process and ensure that Veterans receive the benefits they deserve.

The Secretary's decision to add these presumptives is based on the latest evidence provided in a 2008 independent study by the Institute of Medicine concerning health problems caused by herbicides like Agent Orange.

Veterans who served in Vietnam anytime during the period beginning January 9, 1962, and ending on May 7, 1975, are presumed to have been exposed to herbicides.

More than 150,000 Veterans are expected to submit Agent Orange claims in the next 12 to 18 months, many of whom are potentially eligible for retroactive disability payments based on past claims. Additionally, VA will review approximately 90,000 previously denied claims by Vietnam Veterans for service connection for these conditions. All those awarded service-connection who are not currently eligible for enrollment into the VA healthcare system will become eligible.

This historic regulation is subject to provisions of the Congressional Review Act that require a 60-day Congressional review period before implementation. After the review period, VA can begin paying benefits for new claims and may award benefits retroactively for earlier periods. For new claims, VA may pay benefits retroactive to the effective date of the regulation or to one year before the date VA receives the application, whichever is later. For pending claims and claims that were previously denied, VA may pay benefits retroactive to the date it received the claim.

VA encourages Vietnam Veterans with these three diseases to submit their applications for access to VA health care and compensation now so the agency can begin development of their claims.

Individuals can go to a website at

http://www.vba.va.gov/bln/21/AO/claimherbicide.htm to get an understanding of how to file a claim for presumptive conditions related to herbicide exposure, as well as what evidence is needed by VA to make a decision about disability compensation or survivors benefits.

Additional information about Agent Orange and VA's services for Veterans exposed to the chemical is available at **www.publichealth.va.gov/exposures/agentorange.**

The regulation is available on the Office of the Federal Register website at http://www.ofr.gov/.

The Department of Veterans Affairs (VA)

has announced that Parkinson's disease has been included as a disease associated with Agent Orange.

Additional information about Agent Orange and VA's services for Veterans exposed to the chemical are available at www.publichealth.va.gov/exposures/agentorange

call 1-800-749-8387, press 3 to obtain more information.

Call 1-800-827-1000 to receive the "VA's Guide to Agent Orange Claims"



The Administrative Staff of the Parkinson's Disease Research, Education and Clinical Center



Tonya Belton joined the VA in 1992 as a ward clerk on the hospital floors; she was then promoted and joined the Behavioral Health Clinic as a PSA. In 2004 she accepted a position in the Neurology/PADRECC clinic.

In December 2009, Tonya came over to the PADRECC side permanently and balanced the duties of the front desk (until Yolanda came aboard) and Program Support Associate for the National VA Parkinson's Disease Consortium. In this capacity, Tonya assists Veterans from across the United States in locating a VA clinic that specializes in Parkinson's disease and movement disorders.

Her other responsibilities include assisting the Consortium Chairperson and Coordinator with projects, program development, and grant submissions. She arranges our monthly subcommittee conference calls and records the minutes for those calls. Tonya is also responsible for maintaining the PADRECC/Consortium website.

Dawn McHale serves as the Program Specialist for the Philadelphia PADRECC and is the National Coordinator for the National PADRECC Program and National VA PD Consortium (NVAPDC). She has been with the PADRECC since April 2002.

Dawn is accountable for the overall planning, implementation, and analysis of the daily operation of the local and National PADRECC programs and NVAPDC. Her duties include oversight of the PADRECC clinic, personnel management, and formulation and execution of the annual budget including salaries, travel, supplies, equipment and all other general operating expenses. She assures the fiscal management of the local and national PADRECC/ NVAPDC is maintained on a sound basis in accordance with accounting practices.

Dawn also writes applications and proposals to secure funding for patient/caregiver and professional educational programs.

Yolanda Robinson, our

Patient Services Assistant (PSA) is the first point of contact our patients and visitors encounter. Yolanda began her career at the VA in January 2006 in the Behavioral Health Clinic. In August 2010, she joined the PADRECC.

Yolanda's responsibilities include greeting our patients and visitors, triaging telephone calls, scheduling appointments, consult tracking and management, completing and tracking fee basis requests, and coordinating activities related to registration, eligibility, and beneficiary travel. She maintains our patient demographic database ensuring our information is updated and correct. Yolanda is also responsible for distributing and analyzing our patient satisfaction survey.

Yolanda will develop an action plan and present it to our executive leadership for approval and implementation.

Nurses corner:



Why do we ask you about WHAT and WHEN you are eating?

Heidi Watson, RN

When you come to a visit at the PADRECC, we may ask you about the timing of your medications and what and when you are eating. Why?

There are several dietary considerations for people living with Parkinson's disease. One concern is the potential for protein to interfere with the effectiveness of Parkinson's disease medications. A common drug, levodopa, the primary compound found in Sinemet and Stalevo, can become less effective if taken with food, especially a meal with high amounts of protein. Levodopa and protein use the same pathways to become absorbed in the bloodstream and brain. Therefore, they can be in direct competition with each other to be used by your body Levodopa may not 'win' which can result in 'OFF time' (increase or return of PD symptoms) or a feeling that the medication did not 'kick-in.' Some people living with Parkinson's disease are very sensitive to this interaction of levodopa and protein than others.

How do I know if I am sensitive to interaction?

Examples of foods high in protein include meats, poultry, fish, soy products, cheeses, beans, nuts, milk, and eggs. It is important to include foods with protein in a regular diet to keep your muscular system healthy. If you experience a variable response to your PD medications, one suggestion is to record a food and medication diary. The diary should include what foods you are eating, the times you are eating, and the times that you are taking your PD medications. For example, you may note that when you eat lunch and take your noon dose of Sinemet together, the levodopa does not 'kick-in' at the same rate and you therefore experience 'OFF time'. The diary may reveal that 'OFF time' occurs when you have lunch with protein, such as a roast beef sandwich and a glass of milk. If you notice a pattern of OFF time or delayed response to your medication followed by a mealwith protein, you may in fact be sensitive to this interaction.

What do I do if I am sensitive to an interaction between protein and levodopa?

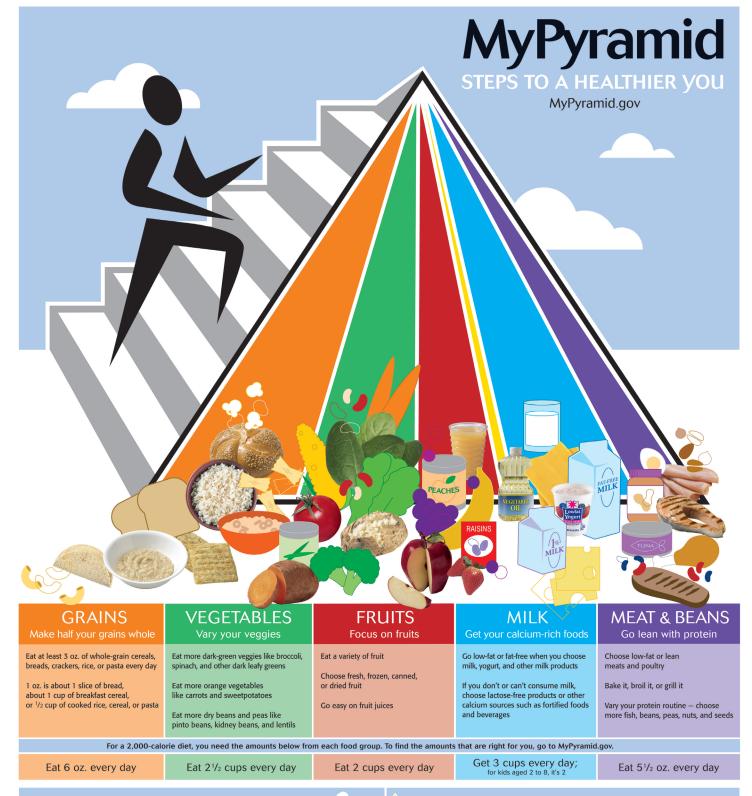
You can talk to your Parkinson's disease provider about changes that you may need to make to your

medication regimen. One common suggestion is to adjust your medication schedule by taking the Sinemet *1 hour before a heavy protein meal* (on an empty stomach or with a light snack such as crackers) or *2 hours after the meal*. Protein is part of a healthy diet and we do not recommend that you stop eating protein. *You should always seek the guidance of a primary care provider or nutritionist before making drastic changes to your diet.*

What to include in a good diet?

The Food Guide Pyramid is a guide for a healthy and balanced diet for adults, including people with Parkinson's disease. The structure of the Food guide pyramid was recently revised (see next page) and includes recommendations of regular exercise. The main message of the pyramid is the same: a healthy diet emphasizes fruits, vegetables, whole grains, fatfree or low-fat milk and milk products, and lean protein while limiting saturated fats, transfats, cholesterol, salt (sodium), and added sugars. (http://www.mypyramid.gov)

For additional information on the potential interaction of protein and levodopa as well as dietary considerations for people with PD, please discuss with your PADRECC provider at your next visit.



Find your balance between food and physical activity

- Be sure to stay within your daily calorie needs.
- Be physically active for at least 30 minutes most days of the week.
- About 60 minutes a day of physical activity may be needed to prevent weight gain.
- For sustaining weight loss, at least 60 to 90 minutes a day of physical activity may be required.
- Children and teenagers should be physically active for 60 minutes every day, or most days.

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Know the limits on fats, sugars, and salt (sodium)

- Make most of your fat sources from fish, nuts, and vegetable oils.
- Limit solid fats like butter, stick margarine, shortening, and lard, as well as foods that contain these.
- Check the Nutrition Facts label to keep saturated fats, trans fats, and sodium low.
- Choose food and beverages low in added sugars. Added sugars contribute calories with few, if any, nutrients.





National VA PD Consortium Centers

The National VA Parkinson's Disease Consortium was established in 2003 as a means to broaden the impact of the Parkinson's Disease Research, Education and Clinical Centers (PADRECCs) and encourage modern Parkinson's disease care across the collective VA Healthcare System. Together, the PADRECCs and Consortium Centers create a hub and spoke model of care, allowing effective and convenient services to all veterans, regardless of locality. Veterans who cannot access services at a PADRECC facility can receive specialized care at the closet Consortium Center in their region.



The National VA Parkinson's Disease Consortium Network

Northeast Consortium Centers

White River Jct., Vermont

Center Director: Timothy Cox, NP Referral Number: 802-295-9363 x5780

Jamaica Plain, MA

Center Director: Dr. Raymond Durso Referral Number: 617-232-9500 x4750

Syracuse, NY

Center Director: Dr. Dragos Mihaila Referral Number: 315-425-3474

Bronx, NY

Consortium Director: Dr. Ruth Walker Referral Number: 718-584-9000 x5915

Pittsburgh, PA

Consortium Director: Dr. David Hinkle Referral Number: 412-688-6185

Baltimore, MD

Consortium Director: Dr. Paul Fishman Referral Number: 410-605-7000 x7060

Cincinnati, OH

Center Director: Dr. Fredy Revilla Referral Number: 513-475-6318

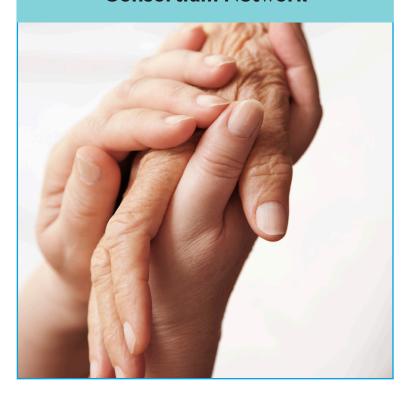
West Haven, Connecticut

Center Director: Dr. Diana Richardson Referral Number: 203-932-5711

Albany, NY

Center Director: Dr. Donald Higgins Referral Number: 518-626-6373

The National VA Parkinson's Disease Consortium Network



VA Benefits Guide Now Available:

The Department of Veterans Affairs' 2011 guide to "Federal Benefits for Veterans, Dependents, and Survivors" is now available on-line @ http://www1.va.gov/opa/publications/benefits_book.asp

The PADRECC would like to thank all of those who made charitable donations on behalf of a loved one followed at the Philadelphia VA PADRECC. The donations are used to support our patient and caregiver education initiatives.

Upcoming Events

Patient & Caregiver Support Group Meetings

Will meet the 1st Tuesday of each month at 1:30 pm starting April 5th in the 4th Floor PADRECC Conference Room. The group will run from April 2011 to December 2011 *This group is for patients who are diagnosed with Parkinson's disease or parkinsonism and their caregivers.

Tele-Support Group for Dementia Caregivers

This group is being held the fourth Wednesday of every month from 1:30pm-2:30pm.

Dial 1-800-767-1750 and when prompted enter code #53860

* This group is for dementia caregivers. The goal of this program is to provide guidance, resources, and support to busy caregivers in a convenient and stress-free manner.

PD 101

This program is for newly diagnosed patients and/or new patients to the PADRECC clinic. The latest information on Parkinson's disease and treatment will be provided. This program will be held on April 12th, 2012, 1:00pm-3:00pm, in the 4th floor PADRECC Conference Room.

Walking this Journey Together: PD from the patient and caregiver perspective

This is a joint patient and caregiver education program with Pennsylvania Hospital's Movement Disorders Center and will be held on April 15th, 2011, registrations is required. If you would like additional information about this event please call Gretchen Glenn, 215-823-5934.

10th Annual Stamp Out Parkinson's (Parkinson's Walk)

On Saturday, **April 16, 2011** walkers and supporters alike will join at Lloyd Hall on Kelly Drive to celebrate the 10th anniversary of the Parkinson's Walk. Gathering at 8:00am for registration and beginning the walk promptly at 9:00am. Please contact The Parkinson's Council for further information on this event. (610-668-4292).

8th Annual Jane C. Wright Patient and Caregiver Symposium

Regenerative Therapy and Genetics of PD.
June 10, 2011 Hilton Philadelphia City Avenue
Please contact Suzanne Reichwein at 215-829-7273 for more information.

Patient and Caregiver PD Support Group Schedule

The group will be held on the 1st TUESDAY
of every month from 1:30pm-3:00pm
in the 4th Floor PADRECC Conference Room.
*topics and speakers may change without notice *

April 5th

Speaker: Heather Cianci, PT Topic: Fall Prevention

May 3th

Speaker: Dr. James Morley, PADRECC Fellow

Topic: Overview of PD Medications

June 7th

Speaker: Gretchen Glenn, LSW PADRECC Social Worker

Topic: Hospitalization and PD

July 6th

Speaker: Julia Libeskind, Speech Language Pathologist

Topic: Speech and Swallowing Complications in

Parkinson's Disease

August 2nd

Speaker: TBA Topic: TBA

September 6th

Speaker: Heidi Watson, RN Topic: Nutrition and PD

October 4th

Speaker: PADRECC Fellow

Topic: TBA

November 1st

Speaker: Eileen Hummel, RN Topic: Yoga in a Chair

Room Change: 9th Floor Nursing Education Center

Large Classroom

December 6th

Speaker: Becky Martine, APRN and Gretchen Glenn, LSW

Topic: Question and Answer Session



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Fax: 215-823-4603

www.philadelphia.va.gov